

Honouring

# Marlene Kalynka



January 29, 1959–June 27, 1996

with the naming of

## Marlene Kalynka Park

Banff, June 27, 2012

**An essay of memories, by her three sisters:**

- Darlene Kalynka
- Karen Kalynka
- Valerie Brown

## **1. About Marlene's Disease**

Epidermolysis Bullosa (EB) is a rare inherited skin disease. People with EB have fragile skin which blisters easily when minor friction or rubbing is applied to the surface. Painful blistering of the skin is caused by the skin's inability to bind together and therefore skin pulls away from the surface membrane fairly easily. There are three main forms of the disease: EB Simplex is characterized as the milder form of the disease; Junctional EB is a more severe form affecting the face, trunk and legs; and Dystrophic EB is the most severe recessive form, characterized by blisters covering large part of the body surface. The latter was the type that Marlene had.

Dystrophic EB causes a person's fingers and toes to fuse together due to excess scarring, leaving behind stumps where fingers and hands once were. The characteristics of this disease include extreme pain, infections, anaemia, malnutrition, and growth retardation. The incidence of EB-affected individuals is rare: EB occurs in only 2 of 100,000 births globally. The chance to live to middle age is possibly less than 1 in a million.

At her birth, the doctor noticed immediately that there was something seriously wrong with Marlene, but he was unable to identify her condition. Marlene was taken to the city hospital where a panel of doctors informed her parents that there was nothing they could do for the baby and sent her home with a diagnosis that her life expectancy was very low. Unable to hold her newborn baby without causing her skin to bruise or fall away, Marlene's mother fed her with an eye dropper and carried her around on a soft foam sponge. Marlene's crib was padded down with this same foam sponge and this is where she would remain for the first three years of her life until her older sister helped release her from her confinement for the very first time at the age of four, allowing her to expand her reach beyond her crib and touch the world around her.

Marlene was called Oceania throughout most of her adult life. This new name was her own decision in her early twenties. Everyone close to her supported that decision and called her 'Oceania'. It is also written 'Oceania' on her grave stone. Therefore, we will use Marlene's self-given new name throughout the rest of this essay.

## **2. The inability of Touch**

An EB child's first experiences with the sense of touch are much different from those experienced by healthy children. Oceania's first experiences with touch were associated with pain as blisters formed on her skin due to friction. Even the clothes she wore could be a source of pain and discomfort. Healthy children learn to crawl and walk by falling and getting back up, but for Oceania, her movement and repeated falls caused her skin to blister and scar. This repeated scarring of her hands and feet caused her fingers and toes to fuse together. Oceania's deformed hands made it difficult for her to write, open doors, hold a fork or brush her teeth. These normal everyday experiences that healthy people take for granted were, for Oceania, challenges that required a lot of imagination and ingenuity for her to overcome.

### **3. From Alvena...**

Darlene was Marlene's older sister and she had the opportunity to grow up with her and help her with all the challenges that accompany the rites of passage that young people experience as they make their way to a mature adult life—like getting a drivers' license, leaving home for the first time, going to dances and music concerts, completing high school and post-secondary education.

Oceania finished grade 10 and she went on to study social work through distance education as a mature student. She received a diploma in social work from the University of Regina. Oceania loved reading and that she won a contest for reading the most books in her grade. She was always visiting the Alvena Regional Library to take out books on horses.

Oceania was determined to hold a driver's license. We drove around in the backyard behind the farmhouse so that she could discover that she could do it, that she could drive a car— something so many take for granted—even though her fingers were webbed and covered with fragile blistering skin. Oceania found ways to be resourceful by wearing ski mitts. She did this so her hands wouldn't hurt. She learned how to drive an automatic and memorized the driver's manual so she could pass her road test.

Every time there was a dance in Alvena's town hall she was on stage dancing and keeping time to the music. She loved music and learned how to play the drums, once again calling on her own resourceful creative nature by using wrist bands that are normally used in tennis, but Oceania used them to fasten the drumsticks to her hands. We have images in our memory of Oceania playing drums on the stage of the then new Alvena town hall.

### **4. To Germany...**

In January 1982, when Oceania was twenty-one, she traveled to Michelberg Germany near Frankfurt to find a treatment for her skin disease. She met, for the first time, other adults and children with EB. Oceania stayed in Germany for four months. Earlier, the community of Alvena had raised money with a walkathon, to send her to Germany. The Kinsmen of Saskatoon recommended her as the key person to sponsor for 'Telemiracle'. They raised about \$15,00.00. Greg Barnsley from C.F.Q.C. T.V. traveled to Germany to interview Oceania for the Telemiracle event held in late March 1982. She was telecast live and made a speech to the entire province of Saskatchewan during the Telemiracle telethon.

The treatment in Germany was initially successful. It involved applying special creams to damaged skin and adhering to a strict diet. Oceania's back, which was permanently raw as a result of the friction incurred by the pressure of sleeping on her back, was healed for the first time in her life. However, the results of the treatment were not long-lasting and the skin eventually broke down once more.

## **5. To Toronto**

The experiences that Oceania had in Germany would give her the confidence to pursue her dream of music and move to Toronto, where she enrolled in classes to become a music editor in a music school. This required moving to Toronto. Again, her determination kicked in and she moved to the big city. Oceania loved music and had the opportunity to attend the Junos as a guest of the well know Canadian musician Larry Gowan. Oceania passed away in Toronto on June 27, 1996.

## **6. Horses were Oceania's passion**

One of the greatest passions in Oceania's life was to own and ride a horse. As her siblings, we searched all over Saskatchewan and Alberta to find a horse quiet enough for her to ride. Valerie would ride it first and if the horse and the ride looked good, and it felt good, Oceania would also get the chance to ride it. Many of these horses were not safe for her to ride. I fell off quite a few, but Oceania made me get back on. To this day we would not dare to imagine what would have happened if she ever fell off. One fall would have most likely killed her. Oceania's body was already covered in raw open sores and it would take 2 hours to patch her up after a bath. Yet she never let fear set in. Plenty of healthy people are scared to go near a horse, let alone ride one. We did finally find a little Arabian mare that she could ride. She rode that little horse for 10 years and it wouldn't hurt her. Oceania even competed in horse shows at the walk-trot and lope paces and won a few ribbons. The funny thing was that if another person rode her little Arabian horse it would bolt away every chance it go. Her passion for horses became Valerie's passion and Valerie went to horse-shoeing school to learn how to cut steel and make a horse shoe and nail it. The greatest thing she learned from sister Oceania is that she refused to take "No" for an answer from life or anyone else.

## **7. A philosophy to survive**

Oceania lived her life to the fullest, always pursuing her dreams with relentless determination and unwavering passion. She was forever grateful to her parents for letting her pursue her desires, whether it was to ride a horse, drive a car, raise Persian cats, live abroad, or fly in a hot air balloon. Her spirit to live life with every fibre of her being, despite the unrelenting pain that she endured, was remarkable. Whenever someone told her she couldn't do something because of the limitations of her disease, she always proved them wrong. Oceania lived because she loved life and all the wonderful things that life has to offer. Karen recalls one particular incident near the end when she insisted on going horseback riding in spite of the cancer ravishing her body. There she was, moaning in pain, as I struggled to get her dressed and put her in a taxi. I recalled begging her to just stay home because I could not bear to watch her in so much pain. It was the longest car ride I ever took with her. I stood back and watched her struggle to get on that horse, but once she was on that saddle she stood up tall and for that half hour ride had a smile on her face. It was then that I realized that Oceania lived to truly experience the joys of life.

## **8. Honoring Marlene Kalyuka**

Oceania would have been very honoured to have this Park named after her. She spent much of her childhood walking here in the evenings when the town was quiet. Oceania took great pleasure flying her kite here and sitting quietly near the train tracks reading while she waited for a train to go by so she could wave. She liked to coach her younger siblings as they practiced for track and field events on these grounds. During baseball tournaments, Oceania was fond of watching the games from a safe distance in order to avoid stray balls and zealous crowds.

Andrew Kalyuka, Oceania's father, would also have been very honoured that the town of Alvena had named the park after his daughter. He dedicated fifteen years of his life being the mayor of Alvena and was very grateful for the community's support in raising funds to send Oceania to Germany for treatment of her disease.